



Quality of life of children with epilepsy: Parent prospective

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ABSTRACT

Background: Epilepsy is thought to be one of the most common neurological disorders and a major cause of impairment in the pediatric age group in Low- and Middle-Income Countries. It has a negative impact on one's physical, cognitive, emotional, and social well-being, as well as one's a general quality of life (QOL). **Aim:** The following study aimed to assess parents' knowledge and reported practice regarding epilepsy as well as their reported quality of life (QOL) of their epileptic children. **Design:** A cross-sectional design was used for this study. **Setting:** This study was carried out in three settings; an outpatient neurology clinic affiliated with Mansoura University Children's Hospital, Mansoura International Hospital, and Mansoura Specialized Hospital, Egypt. **Subjects:** Non-probability convenience sampling of 156 parents of epileptic children aged between 6 – 15 years of both sexes. **Tools:** Two tools were used to collect the data namely: A self-administrated Questionnaire Sheet and The Quality of Life in Childhood Epilepsy (QOLCE-55) scale. **Results:** The reported parents' QOL of their epileptic children got higher scores in physical and emotional domains while getting a lower score in cognitive and social domains. **Conclusion:** Our study concluded that epileptic children's overall QOL was compromised, with a significant impact on those children's cognitive and social domains. Also, there is a significant relationship between parents' total knowledge, reported practice score, and the total mean score of the QOL scale. Furthermore, the characteristics of studied epileptic children, their clinical profiles, and their parents' characteristics are factors associated with poorer QOL. **Recommendation:** The study recommended investigating the quality of life of epileptic children from the child's perspective.

Key words: Parent, quality of life (QOL), children, epilepsy

Introduction

Epilepsy is a common chronic neurological disorder characterized by recurrent seizures. The prevalence of epilepsy in children in underdeveloped nations ranged from 0.004 to 0.008% (Almutairi, et al, 2016 and Shihata, et al, 2021). Due to the extremely demanding nature of childhood and the high incidence of the epilepsy among children, with a prevalence rate of roughly 3-4 per 1,000 children, seizures in children are more problematic and require more detailed considerations. Epilepsy is the most common stigmatizing neurological disorder marked by repeated seizures (Al-Dossari et al, 2018). In Egypt, the prevalence rate of epilepsy was found to be 9.3/1000, while the incidence rate is 1.5/1000. Males have a slightly higher frequency of epilepsy than females, and the early and late childhood period has the greatest prevalence rate (Khedr et al, 2013).

Over the last several decades, global knowledge regarding epilepsy and its consequences on children and caregivers has improved (Asiri et al, 2015). Parents reported that their child with epilepsy was negatively affected by stigma, behavior at school, and memory/ concentration problems (Hassan, Yahya, Tariq, Hussamaldin Tariq, 2018). The common misconceptions in epilepsy include the overprotection of children with

epilepsy from their families by preventing them from sharing in sports or social activities and going to school which led to high levels of anxiety and lacking of confidence (Hagemann et al, 2016). Because of the unexpected nature of seizures, children with epilepsy suffer not only physical hazards such as falls and burns but also social and psychological stigmatization, lack of understanding, isolation, and uncertainty (Al-Dossari et al, 2018 and Osman et al, 2021).

Especially for children, to achieve adequate seizure control, lower the risk of status epileptics, and limit the frequency of inpatient hospitalizations, diagnostic and therapeutic methods must frequently be exhausted early in the disease. In addition, to increase the quality of life (QOL) of children and caregivers, a second focus should be placed on the improvement of concurrent illnesses, training, or acceptance of physical or cognitive limitations (Riechmanna et al., 2019).

Epilepsy management requires an understanding of the impact of epilepsy on all aspects of a child's life. Traditionally, the management of epilepsy centered on controlling episodes of seizure and with little attention paid to QOL (Pachange, Dixit, Arjun & Goel, 2021). Epilepsy in children is associated with several comorbidities. It is generally understood that children with epilepsy have a worse health-related QOL, which can

influence them in physical, psychological, social, and educational domains (**Karnavat, Hegde & Kulkarni, 2018**). Epilepsy in childhood has been linked to negative psychosocial consequences. This includes anxiety and depression, low self-esteem, behavioral problems, and academic achievement. The problems related to social competence, behavior, emotions, academic, and family life can continue throughout adulthood. In addition, there is a significant therapeutic gap. In children with epilepsy, QOL is linked to the treatment gap and higher morbidity (**Olusanya, Wright, Nair et al, 2020; Adla, Gade, Puchchakayala et al, 2017; Nadkarni, Jain & Dwivedi, 2011 and Aggarwal & Datta, 2011**). Many studies on the QOL in children with epilepsy have highlighted the risk of developing a number of socio-cultural and psychological problems in affected children, such as lower self-esteem and higher levels of anxiety and depression, regardless of physical problems of the disease or those accompanying drug side effects. Furthermore, children with epilepsy are more likely to experience difficulties in school, as well as social withdrawal and isolation (**Katibeh, Inaloo, Jafari, Fattah & Mazloomi, 2020**).

Despite significant advances in epilepsy medicine, the negative impression associated with the word "epilepsy" still has a greater influence on children than the disease itself or drug side effects in some societies. Epilepsy has a significant impact on

the quality of life, not only because of the disease's chronicity or the typical drugs used or their side effects, but also because of intolerances, biases, and societal issues that still happen (**Goti1, Dihora & Desai, 2020**).

Significance

Epilepsy is still the most common chronic neurological condition in Low- and Middle-Income Countries. Epilepsy has an impact on the physical, emotional cognitive, social wellbeing, as well as the overall QOL. Children with epilepsy are at risk of impaired QOL. When a person has a chronic illness for which complete treatment is difficult, QOL is considered a significant healthcare outcome measure (**Nagabushana, Praveen-Kumar & Agadi, 2019**). There are few studies on the quality of life of epileptic children from developing countries like Egypt. The current study aims to fill the research gap by assessing the QOL in children with epilepsy. On reviewing several publications in Egypt, we found limited information about this study.

Aim of the study

The aim of the following study was to assess parents' knowledge and reported practice regarding epilepsy as well as their reported quality of life of their epileptic children.

Operational definitions:

Quality of life (QOL): is a measure of an individual's ability to function physically, emotionally, and socially within his/her environment at a level consistent with his/her own expectations.

Epilepsy: is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of this condition. This definition requires the occurrence of at least one epileptic seizure.

Subject and Methods:

Study design:

A descriptive cross sectional design was used for this study.

Research questions:

The following research questions are posed:

Is there a relationship between parents' knowledge and reported practice regarding epilepsy and their children's quality of life?

What are the factors correlated with the poorer quality of life of their children with epilepsy?

Is there a relationship between parents' perceived impact of epilepsy and their children's quality of life?

Setting:

This study was carried out in three settings; an outpatient neurology clinic affiliated with Mansoura University Children's Hospital, Mansoura International Hospital, and Mansoura Specialized Hospital, Egypt.

Subjects and sampling:

The subjects were chosen by convenience sampling from 156 epileptic children's parents attending the previously mentioned setting, willing to share in the study and fulfill the following criteria: Parents of children aged between 6 to 15 years of both sexes who have had a confirmed diagnosis of epilepsy for at least 6 months.

1-Parents of epileptic children who do not have any other comorbid neurodevelopmental disorders (such as mental retardation, developmental delay, autism, cerebral palsy, behavioral disorders, attention deficit hyperactivity disorder, a neurodegenerative disorder, and visual/hearing impairment), or chronic medical problems (asthma, hypertension, chronic lung disease, chronic renal failure, thalassemia, hypothyroidism, etc.) and children whose primary caregiver was unavailable to complete the questionnaire were excluded from the study.

Sample size calculation:

The sample size was calculated using the following formula for a single population proportion: - $n = (Z_{\alpha/2})^2 p(1-p) / d^2$

$$n = (1.96)^2 \cdot 0.103(0.897) / (0.05)^2 = 142$$

Where: n : is "the donated sample size."

" $Z \cdot a/2$ ": reliability coefficient of standard error at a significance level of 5% with $Z=1.96$

According to **Elsakka, El Said, Aly, Ibrahim & Abd Elmaksoud (2021)**, P is the estimated proportion of an attribute is 10.3%.

d:Margin of error (5% is accepted)

The sample size was determined using the formula above (142). By adding in a 10% non-response rate, the total sample size was calculated to be $142+14=156$.

Tools of Data Collection:

Two tools were used to collect the data, namely: A self-administrated Questionnaire Sheet which was created by the authors after revising related current literature and research studies; and The Quality of Life in Childhood Epilepsy (QOLCE-55) scale (**Nishina & Yoshioka, 2018; Hassan, Yahya, Tariq & Hussamaldin Tariq, 2018; WHO, 2019 and Elmohalem, Ismail, & Bayomi, 2020**).

Tool I: A self-administrated Questionnaire Sheet: It was created by the researchers and included four parts:

Part I: Parents' characteristics such as age, occupation, level of education, residence, marital status, and family income.

Part II: Children's characteristics; age, gender, birth order, and education. Clinical profiles such as the age of onset, type of seizures, duration and frequency of seizures, whether or not the seizures are preceded by precipitating factors, and whether or not the child has an aura prior to seizure

Part III: Parents' knowledge and reported practice toward epilepsy: It involved questions about the concept of epilepsy, its causes, predisposing factors, diagnostic procedure, types of epileptic fits, treatment modalities, antiepileptic medications' dose, side effects, and management before, during, and after an epileptic attack. This questionnaire is composed of multiple-choice questions.

Part IV: Impact of epilepsy on the child's life: academic achievement, daily activities, and finally, the child's communication with the outside society from the parents' point of view.

Scoring system

The scoring system for each parent was calculated by summing up the scores of all questions for total knowledge and reported practice. Scores then were categorized as total knowledge scores (equal 40 points); unsatisfactory knowledge: $< 60\%$ of the total scores; and satisfactory knowledge: $\geq 60\%$ of the total scores. Total reported practice score (35 points); incompetent practice: $< 60\%$ of the total

scores and competent practice: $\geq 60\%$ of the total scores (Elmohalem, Ismail & Bayomi, 2020).

Tool II: The Quality of Life in Childhood Epilepsy (QOLCE-55) scale was used. QOLCE55 is a validated questionnaire. ⁽²³⁾ Professional translators translated the questionnaire into Arabic. All precautions were exercised to retain the meaning, grammar, and simplicity of the original version. A self-administered Arabic version of the QOLCE-55 questionnaire was given to the parents. Parents must answer 55 questions about how often their children experience certain problems compared to other children of their age during the past 4 weeks. QOLCE-55 item allocation contained the following domains: cognitive functioning (22 items asking about some problems children might have with concentrating, remembering, and speaking); emotional functioning (17 items that describe how children might feel in general and some children's behavior); social functioning (7 items describing some children's social interactions and activities); and physical functioning (9 items asking about physical activities that children might do). Each item is scored on a six-point Likert scale, with anchors that (e.g., 1 = very often, 2 = fairly often, 3 = sometimes, 4 = almost never, 5 = never, 6 = non-applicable).

Scoring Instructions

Recode all of the items such that higher scores reflect higher well-being. Scores are linearly converted to a 0 to 100 point scale (1 = 0, 2 = 25, 3 = 50, 4 = 75, and 5 = 100). Scores are composed of averages for each of the four domains, and the total QOL score is derived by summing all the individual scores. Higher scores indicate a better or good QOL. Patients with scores ≥ 75 are considered to have a good QOL (Ferro, Goodwin, Sabaz, Speechley, 2016).

Validity and reliability

The validity of the developed tool was tested for content and face validity by five experts in pediatric nursing. They evaluated the content validity of the developed tool. Additionally, a pilot study was done to evaluate the face validity of the designed tool on 10% of epileptic children's parents (16 parents) and was excluded from the studied sample. The pilot study aimed to evaluate the clarity and applicability of the research tools, in addition to estimating the approximate time required for data collection. Accordingly, the necessary modifications of both experts and piloted parents were executed; some questions have been added while others have been deleted. Internal consistency reliability (Cronbach's α) for Tool I part (III & IV) emerged as good (Cronbach's $\alpha = 0.87, 0.71$ respectively). The QOLCE has a high

level of internal consistency. A Cronbach's α value ranging from 0.72 to 0.93 across subscales has been reported, with an overall QOLCE score of 0.93 confirming internal consistency reliability.

Procedures of Data Collection:

- The preparatory phase, which includes a study of relevant literature on various aspects of the problem. This review aided the researchers in understanding the true scope and severity of the problem and aid in the development of study tools.
- Prior to data collection, the medical and nursing directors of the above-stated settings gave formal permission to conduct the study following a thorough description of the study's goals and expected outcomes. Parents' permission was obtained verbally after the study's goal was explained. Total confidentiality of any acquired information was ensured, and these were to be used only for the research purpose. The research sample's rights, privacy, and safety were all protected.
- The real fieldwork began in May 2021 and lasted until December 2021. It began with interviews with epileptic children's accompanying parents in the above-mentioned settings. The researchers began by introducing themselves to the study subjects and giving

them a brief overview of the study's purpose then distributed the study tools.

- In addition, a Google Form was used to implement a pre-scheduled online questionnaire, and then it was sent as a message through a WhatsApp group. A Google Form was used to facilitate distributing and collecting the data.

Ethical considerations:

The research ethics committee of the Faculty of Nursing, Mansoura University, gave its ethical approval before conducting the study. To obtain approval for the study, an official letter from the dean of Mansoura University's Faculty of Nursing was sent to Mansoura University Children's Hospital, Mansoura International Hospital, and Mansoura Specialized Hospital; verbal informed consents were also obtained from the children's parents after explaining the study's purpose.

Statistical analysis:

The data was coded and put into SPSS version 24 (Statistical Package for Social Sciences). Following full entry, the data was examined for any errors before being evaluated by the same program and presented in frequency tables with percentages. Numbers and percentages were used to represent qualitative data. The arithmetic mean and standard deviation were also used to describe quantitative data. The relationship and/or difference between

categorical variables were tested using a one-sample t-test. For $p < 0.05$, the results were considered statistically significant.

Results:

The characteristics of the studied parents are presented in **Table (1)**. More than two-thirds of them (67.3%) were mothers; married (65.4%) with a mean age of 32.27 ± 5.07 years. Slightly more than half of them had secondary education (53.8%), were housewives (53.8%), and had insufficient income (50.6%). More than two-thirds of the studied parents (68.6%) resided in rural areas.

Table (2) shows the characteristics of epileptic children. Regarding age, it was found that slightly more than half of them (51.3%) were aged 12-15 years old, with a mean age of 12.9 ± 2.32 years. 55.1% were girls, and 53.8% of those children were second in birth order. Approximately two-thirds of them were in primary school (60.9%). In more than half of the children in the study sample, the duration of epilepsy was less than 4 years (55.8%). The seizures mostly occurred 3 to 5 times per month (80.8%), lasted for 3 to 5 minutes (57.1%), and were preceded by precipitating factors (69.2%). In addition, 60.9% of those children had generalized tonic-clonic seizures, and 51.9% of them had an aura before the seizure.

Parents' knowledge about epilepsy was summarized in **Table (3)**, The majority of parents scored as

having unsatisfactory knowledge of the concept, causes, diagnostic procedures of epilepsy, types and triggering factors of epileptic fits, treatment modalities, dose, and side effects of antiepileptic drugs (89.7%, 84.6%, 69.9%, 90.4%, 62.8%, 65.4%, 62.2%, respectively). Concerning parents' reported practice before, during, and after epileptic attacks, approximately two-thirds reported inappropriate precaution measures for the child before and during the attack, and 89.7% of parents couldn't identify and report the care of an epileptic child after the epileptic attack.

Parents' perceived impact of epilepsy on their child's life is presented in **table (4)**. Most of the parents stated that epilepsy affected the child's communication within and outside the family and the child's social relationships (64.1% and 56.4% respectively). Also, 82.1% reported that epilepsy impacts their daily activities. On the other hand, 80.1% consider epilepsy an obstacle to a child's sporting or social activities. Furthermore, 60.3% and 69.9% of the parents stated that their child suffers from a school problem because of his disease and frequently misses school days. 72.4% and 26.9% of parents reported that their children have lower academic achievement than others and has a previous academic failure.

Table (5) illustrated that the reported parents' QOL of their epileptic children got higher scores in

physical and emotional domains while they got lower scores in cognitive and social domains, with a total mean score of QOL of 53.6 ± 24.27 , scales reflecting a poorer QOL.

Table (6) indicated that there is a significant relationship between studied epileptic children's characteristics; their clinical profiles including age, gender, academic year, seizures frequency and duration of seizures, and the total mean score of the quality of life scale.

Table (7) explained that there is a significant relationship between studied parents' characteristics, including age, level of education, occupation; marital status, income, residence, and the total mean score of the QOL scale. Also, there is a significant relationship between the total score of knowledge; reported practice, and the total mean score of the QOL scale.

Table (1): Distribution of socio-demographic characteristics of the studied parents:

| Socio-demographic characteristics | N= (156) | % |
|-----------------------------------|---------------------|------|
| Parents | | |
| Father | 51 | 32.7 |
| Mother | 105 | 67.3 |
| Age | | |
| 18-<28 | 15 | 9.6 |
| 28- <38 | 102 | 65.4 |
| 38-<48 | 39 | 25 |
| X ± SD | 32.27 ± 5.07 | |
| Level of education | | |
| Knows read and write | 12 | 7.7 |
| Primary | 8 | 5.1 |
| Preparatory | 6 | 3.8 |
| Secondary | 84 | 53.8 |
| University | 46 | 29.5 |
| Occupation | | |
| House wife/not working | 66 | 42.3 |
| Governmental work | 51 | 32.7 |
| Free work | 39 | 25 |
| Marital status of parents | | |
| Marriage | 102 | 65.4 |
| Divorce | 46 | 29.5 |
| Widow | 8 | 5.1 |
| Income | | |
| Enough | 77 | 49.4 |
| Not enough | 79 | 50.6 |
| Residence | | |
| Urban | 49 | 31.4 |
| Rural | 107 | 68.6 |

Table (2): Distribution of the studied epileptic children characteristics and their clinical profiles:

| Children characteristics | N= (156) | % |
|---------------------------------------------------|---------------------|------|
| Age | | |
| 6 - < 12ys | 76 | 48.7 |
| 12- 15ys | 80 | 51.3 |
| X ± SD | 12.19 ± 2.32 | |
| Gender | | |
| Boy | 70 | 44.9 |
| Girl | 86 | 55.1 |
| Birth order | | |
| First | 60 | 38.5 |
| Second | 84 | 53.8 |
| Third | 7 | 4.5 |
| Fourth and more | 5 | 3.2 |
| Academic year | | |
| Primary | 95 | 60.9 |
| Preparatory | 53 | 34.0 |
| Secondary | 8 | 5.1 |
| Onset / Duration (years) | | |
| < 4ys | 87 | 55.8 |
| 4 - < 8ys | 41 | 26.3 |
| 8 - 12ys | 28 | 17.9 |
| Type of seizures | | |
| Generalized tonic | 18 | 11.5 |
| Generalized tonic-clonic | 95 | 60.9 |
| Simple partial | 12 | 7.7 |
| Complex partial | 31 | 19.9 |
| Seizure frequency /month | | |
| 1-2 | 30 | 19.2 |
| 3-5 | 126 | 80.8 |
| Seizures preceded by precipitating factors | | |
| Yes | 108 | 69.2 |
| No | 48 | 30.8 |
| Duration of seizures (minutes) | | |
| 1-2 | 67 | 42.9 |
| 3-5 | 89 | 57.1 |
| Child has aura before seizure | | |
| Yes | 75 | 48.1 |
| No | 81 | 51.9 |

Table (3): Distribution of the studied parents' knowledge and reported practice categories score about epilepsy

| Items | N= (156) | | | |
|----------------------------------|--------------------------|------|------------------------|------|
| | Unsatisfactory knowledge | | Satisfactory knowledge | |
| | No. | % | No. | % |
| Parents' knowledge: | | | | |
| The concept of epilepsy | 140 | 89.7 | 16 | 10.3 |
| Causative factors of epilepsy | 132 | 84.6 | 24 | 15.4 |
| Diagnostic procedure of epilepsy | 109 | 69.9 | 47 | 30.1 |

| | | | | |
|-----------------------------------------------|----------------------|------|--------------------|------|
| Types of epileptic fits | 141 | 90.4 | 15 | 9.6 |
| Triggering factors of epileptic fits | 98 | 62.8 | 58 | 37.2 |
| Treatment modalities of epilepsy | 102 | 65.4 | 54 | 34.6 |
| Dose and side effects of anti-epileptic drugs | 97 | 62.2 | 59 | 37.8 |
| Parents' reported practice: | | | | |
| Items | Incompetent practice | | Competent practice | |
| | No. | % | No. | % |
| Before epileptic attack | 96 | 61.1 | 60 | 38.5 |
| During epileptic attack | 104 | 66.7 | 52 | 33.3 |
| After epileptic attack | 140 | 89.7 | 16 | 10.3 |

Table (4): Distribution of the studied parents' perceived impact of epilepsy on the child's life

| Items | N= (156) | | | |
|------------------------------------------------------------------------|----------|------|-----|------|
| | Yes | | No | |
| | No. | % | No. | % |
| Epilepsy affected child' communication within and outside the family | 56 | 35.9 | 100 | 64.1 |
| Epilepsy affected child's social relationship | 68 | 43.6 | 88 | 56.4 |
| The child should be kept away from others | 97 | 62.2 | 59 | 37.8 |
| Epilepsy doesn't impact the child's daily activities | 28 | 17.9 | 128 | 82.1 |
| Epilepsy is not an obstacle on a child's sporting or social activities | 31 | 19.9 | 125 | 80.1 |
| The child suffer from school problem because of his disease | 94 | 60.3 | 62 | 39.7 |
| The child is frequently missing school days | 109 | 69.9 | 47 | 30.1 |
| The child has lower academic achievement than others | 113 | 72.4 | 43 | 27.6 |
| The child has previous academic failure | 42 | 26.9 | 114 | 73.1 |

Table (5): Frequency distribution of four subscales of the Quality of Life scale

| Items | No. of Questions | Total number of parents =156 | |
|---------------------------------------------|------------------|------------------------------|--------------|
| | | Means | SD |
| Cognitive functioning | 22 | 53.8 | 32.22 |
| Emotional functioning | 17 | 56.3 | 29.51 |
| Social functioning | 7 | 48.4 | 22.74 |
| Physical functioning | 9 | 55.9 | 12.24 |
| Total score of quality of life scale | 55 | 53.6 | 24.27 |

Table (6): Relationship between studied epileptic children characteristics, their clinical profiles, and total score of quality of life scale

| Items | Total score of quality of life scale | |
|--------------------------------|--------------------------------------|----------|
| | T test | P. value |
| Age | .729** | .000** |
| Gender | .196** | .001* |
| Birth Order | .053 | .366 |
| Academic year | .192** | .001* |
| Onset / Duration (years) | .193** | .001* |
| Type of seizures | -.052 | .380 |
| Seizure frequency /month | .747** | .000** |
| Duration of seizures (minutes) | -.191** | .001* |

** Correlation is significant at the 0.01 level (2-tailed).

Table (7): Relationship between studied parents' characteristics, total knowledge and total reported practice score and total score of quality-of-life scale

| Items | Total score of quality of life scale | |
|-------------------------------|--------------------------------------|----------|
| | T test | P. value |
| Age | .433** | .004** |
| Level of education | .459** | .002** |
| Occupation | .305* | .030* |
| Marital status | .521** | .001** |
| Income | .503** | .001** |
| Residence | .357* | .020* |
| Total knowledge score | .695** | .000** |
| Total reported practice score | .521** | .002** |

Discussion

Epilepsy is thought to be one of the most common neurological disorders and a major cause of impairment in the pediatric age group in Low- and Middle-Income Countries. In order to improve the well-being of children with epilepsy, the primary caregiver must go beyond seizure control (Nagabushana, Praveen-Kumar & Agadi, 2019). To our knowledge, there has been little research on epileptic children's quality of life in Egypt. As a result, it is essential to understand the predictors of quality of life in Egyptian children with epilepsy. The aim of the following study was to assess parents' knowledge and reported practice regarding epilepsy in addition to the reported quality of life of their epileptic children.

The characteristics of the present study sample of parents indicated that more than two-thirds of them were mothers, residing in rural areas, and married with a mean age of 32.27 ± 5.07 years. Slightly more than half of them had secondary education, were housewives, and had insufficient income (table 1). These results are consistent with the findings of

Shahin & Hussien, (2021) who assessed the effect of a structured educational intervention program on the knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy and found that most caregivers were married females, and mainly mothers, with a mean age of 31.3 years. Almost half of them had secondary education. The majority was not working, had insufficient income, and resided in rural areas.

According to the current study results, slightly more than half of the studied children were girls, second in birth order, the duration of epilepsy was less than 4 years; the seizures mostly occurred 3 to 5 times per month, lasted for 3 to 5 minutes, and were preceded by precipitating factors; an aura before the seizure; and about two thirds of those children had generalized tonic-clonic seizures (Table 2). These matches with the result conducted by (Shahin & Hussien, 2021) who reported that; two thirds of studied children with epilepsy being girls and most of those children were second in birth order. The duration of epilepsy in two-thirds of children was less than 4 years. The seizures mostly occur 3 to 5 times per month (81.7%), last

for 3 to 5 minutes (61.7%), and are preceded by precipitating factors (71.7%). Researchers' point of view regarding the frequency of seizures might be due to the lack of mothers' awareness about the child's condition, the negligence of some parents about drug compliance, and the exposure of children to seizure aggravating factors.

The present study revealed that the majority of parents scored as having unsatisfactory knowledge toward the concept, causes, and diagnostic procedures of epilepsy; types and triggering factors of epileptic fits; treatment modalities; and dose and side effects of anti-epileptic drugs. Approximately two-thirds reported inappropriate practice before, during, and after an epileptic attack (**Table 3**). Similar to the results of our current research study, many studies conducted in KSA showed the same results as the level of knowledge was significantly poor (**Alqahtani, 2015; Almutairi et al , 2016 and Neyaz et al, 2017**). **Al.Zubaidi et al, 2017**, added that most of the Saudi parents had poor knowledge regarding epilepsy, which resulted in practice misconceptions. Furthermore, the results of **Elmohalem, Ismail & Bayomi, (2020)** revealed that the majority of the studied parents had a low level of knowledge about epilepsy and that the majority of the studied parents' total care practice score was incompetent. In contrast to the results of our study, **Hassan, Yahya, Tariq, Hussamaldin Tariq, (2018)** found that the majority of Saudi

parents in Abha presented adequate awareness about epilepsy in children as well as showed an adequate attitude and practice pattern.

Regarding parents' perceived impact of epilepsy on the child's life, most of the parents reported that epilepsy affected the child's communication within and outside the family and the child's social relationships and daily activities. In addition, they considered epilepsy an obstacle to a child's sporting or social activities. Besides, their children suffer from school problems, frequently miss school days, have lower academic achievement than others, and have a previous academic failure (**Table 4**). These results are supported by **Jonsson, Jonsson & Eeg-Olofsson, (2014)** who stated that the impact of epilepsy on a child is a combination of physical consequences of the seizure, the effect on the social position, and the physiological outcome or both of them. Additionally, children with epilepsy are at an increased risk of behavioral, emotional, cognitive, social, and psychiatric problems that can adversely affect children's developmental outcomes and are considered to be more handicapping than the seizure manifestation itself.

From the researchers' point of view, these results show that epilepsy has a considerable impact on QOL and these results might be due to seizure complications such as learning difficulties, and the fact that parents tend to over-protect their sick child

especially if the child has a chronic illness as epilepsy. Furthermore, more attention is being focused on problems experienced by epileptic children as a result of stigma, which is linked to low self-esteem, physical limitations, low energy levels, and negative psychosocial health effects. Also, epilepsy may interfere with social functioning by decreasing educational chances and interpersonal interactions. In addition, continuing with education is the most common concern and the future worry of the parents about the ability to continue with schoolwork. Moreover, the most prevalent worries in children and adolescents suffering from epilepsy were when having or starting a relationship with others, and what their teachers and colleagues would think if they suffer a seizure at school.

On the other hand, these results disagree with the results of **Horaib, Alshamsi, Zabeeri et al. (2021)** who assessed the impact of epilepsy and its treatment on the QOL, development, and opportunities for children and adolescents with epilepsy in the Eastern Province of the Kingdom of Saudi Arabia and found that 25.8% didn't go to school regularly and missed school days compared to 74.2% who went to school regularly, 84.95% of the epileptic children had no previous academic failure and 24% of them missed school days. In relation to causes of school irregularity, 20.8% missed school because of their illness periods,

while 50% didn't go to school regularly because of their parent's fear of their children's exposure to fits in school.

The results of the current study illustrated that the epileptic children got a higher score in physical and emotional domains while got a lower score in cognitive and social domains with a total mean score of QOL 53.6 ± 24.27 scales which reflects a poorer QOL (**Table 5**). These findings to some extent were in accordance with the results of **Ahmed, Nada, El'aidya & Mohammad, (2020)** who discovered that children with epilepsy scored higher in the physical and academic domains than in the emotional and social domains.

While these findings were in contrast to previous publications, **Arya, Gehlawat, Kaushik & Gathwala, (2014)** reported that the overall mean QOL score was 66.7 ± 4.83 . **Karnavat, Hegde & Kulkarni, (2018)** investigated the QOL in children with epilepsy in both the private and drawn 601 private and public setting children and adolescents with epilepsy and their parents, reported that the overall PedQOL score was 67.21 ± 29.391 and 78.66 ± 9.161 in private and public settings, respectively; which is more than in our study.

Additionally, **Pachange, Dixit, Arjun & Goel, (2021)** found that the total mean QOL score based on the QOLCE-55 scale is 69.9 ± 13.43 . Physical

functioning was the most compromised of the four scales assessed, having the lowest mean QOL score. Social functioning, which includes social interactions and social activities, was the least affected.

It is clear from this study's results that there was a significant relationship between studied epileptic children's characteristics and their clinical profiles including age, gender, academic year; seizures frequency and duration of seizures, and the total mean score of the QOL scale (**Table 6**). These findings could be interpreted as more than half of the studied epileptic children were adolescent girls; because of the social and cultural factors, as there for older boys' children, there is more availability, opportunity, and the option of participating in most outdoor activities than for females' children. Cultural factors may also play a role in decreasing the QOL of girls because girls receive less attention and care than boys in some households.

Furthermore, girls and boys may have differing sensitivities to the QOL domains. These results are in harmony with **Cianchetti, Messina, Pupillo et al. (2015)** who reported poorer quality of life in older adolescents (aged 14-17 years). Overall older children's quality of life was affected more than younger children. **Ferro et al, (2017)** mentioned that longer disease duration and seizure severity was associated with a poorer QOL.

Additionally, **Pachange, Dixit, Arjun & Goel, (2021)** concluded that the QOL was significantly affected by the child's age, age at the first seizure, and time since the last seizure. The type of seizures did not appear to be a significant factor in determining epileptic children's QOL. Furthermore, the results of **Horaib, Alshamsi, Zabeeri, et al. (2021)** show that boys and adolescents have a higher quality of life than girls and children. Boys and adolescents with higher family incomes and socioeconomic status had a better quality of life. However, seizure frequency and longer treatment duration had unfavorable effects on QOL.

The current study results explain that there is a significant relationship between studied parents' characteristics, including age, level of education, occupation; marital status, income, residence, and the total mean score of the QOL scale. Also, there is a significant relationship between the total score of knowledge, reported practice, and the total mean score of the QOL scale (**Table 7**). As in our study, the authors **Adla et al, (2017) and Anguzu et al, (2021)** found that mothers' education, age, frequency of seizures, mother's education, and epilepsy type were major predictors of quality of life in epileptic children. Adolescents with epilepsy who live in rural areas are from the poorest families, are more likely to drop out of school, have

the lowest quality of life, and those with poor seizure management are the most affected.

In contrast to our study, a previous publication by **Riechmanna et al., (2019)**, found that there is no significant influence of gender, age, or disease duration on the QOL of children and adolescents. Additionally, these findings are inconsistent with **Arya, Gehlawat, Kaushik & Gathwala, (2014)** who found that the total QOL of children with epilepsy was unaffected by parental education, socioeconomic level, seizure frequency, or type of epilepsy.

Conclusion

Our study concluded that epileptic children's overall quality of life was compromised, with a significant impact on those children's cognitive and social domains. Also, there is a significant relationship between parents' total knowledge, reported practice score, and total mean score on the QOL scale. Furthermore, the characteristics of studied epileptic children, their clinical profiles, and their parents' characteristics are factors that are associated with a poorer quality of life. In addition, parents perceived that epilepsy affected the child's communication within and outside the family, the child's social relationships, and daily activities. Moreover, they perceived that their children suffer from school problems, frequently miss school days,

and have lower academic achievement and previous academic failure.

Recommendations

- Investigate the quality of life of epileptic children from the child's perspective.
- Assessment of parents' quality of life is an essential health outcome when assessing the health of children with epilepsy.
- More research is needed to enhance the quality of life in epileptic children and how to use it in personalized care and successful epilepsy management.
- Further research is proposed on a completely randomized control trial design for more strong evidence.
- Repeat the study with a large sample size from different governorates in Egypt.
- Further awareness programs are important to improve the overall quality of life for children with epilepsy and their caregivers.

References

Adla N, Gade A, Puchchakayala G, et al. (2017). Assessment of Health Related Quality of Life in Children with Epilepsy Using Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55) in

Tertiary Care Hospital. *J Basic Clin Pharm* 2017; 8:74–77

Aggarwal A & Datta V. (2011). Quality of life in children with epilepsy. *Indian Pediatrics*. 48: 893-896.

Ahmed NS, Nada MA, El'aidyda MD& Mohammad AS. (2020). Quality of Life in Childhood Epilepsy. *Med. J. Cairo Univ.*, 88 :(4) September: 1477-1485

Al-Dossari KK, Al-Ghamdi S, Al-Zahrani J, Abdulmajeed I, Alotaibi M, Almutairi H et al. (2018). Public knowledge awareness and attitudes toward epilepsy in Al-Kharj Governorate Saudi Arabia. *J Family Med Prim Care*, 7:184-90.

Al.Zubaidi AM, Alsudairy NM, Alzubaidi BA, Joharji RN, AlQurashi SM, Alsadi KA, Abulela AA. (2017). Assessment of Knowledge and Attitude and Practice of Parents towards Epilepsy among Children in Jeddah City. *The Egyptian Journal of Hospital Medicine*, 69 (6): 2685-2689

Almutairi AM, Ansari T, Sami W et al. (2016): Public knowledge and attitudes toward epilepsy in Majmaah. *J Neurosci Rural Pract*. 7:499-503.

Alqahtani JM (2015). Knowledge and practice of schoolteachers towards students with epilepsy in Khamis Mushate, Southern Saudi Arabia. *Journal of Family and Community Medicine*, 22:163-168.

Anguzu R, Akun P, Katairo T, Abbo C, Ningwa A, Ogwang R, Mwaka AD, Marsh K, Newton CR & Idro R. (2021). Household poverty, schooling, stigma and quality of life in adolescents with epilepsy in rural Uganda. *Epilepsy Behav.*; 114(Pt A):107584. doi: 10.1016/j.yebeh

Arya V, Gehlawat VK, Kaushik JS, Gathwala G. (2014). Assessment of parent reported quality of life in children with epilepsy from Northern India: A cross-sectional study. *Journal of Pediatric Neurosciences*. Jan-Apr (9):17-20

Asiri NA, Bin Joubah MA, Khan SM et al. (2015). Maternal knowledge of acute seizures. *Neurosciences (Riyadh, Saudi Arabia)*, 20:346-349.

Cianchetti C, Messina P, Pupillo E, et al. (2015). The perceived burden of epilepsy: impact on the quality of life of children and adolescents and their families. *Seizure*. 24:93-101. 10.1016/j.

Elmohalem R., Ismail S & Bayomi M. (2020). Assessment of Parents' Knowledge, Practices and Attitude toward Care for Their Epileptic Children. *Egyptian Journal of Health Care*, 11(3): 144-162. doi: 10.21608/ejhc.2020.109226

Elsakka E, El Said H, Aly S, Ibrahim E & Abd Elmaksoud M. (2021). Knowledge, Skills, and Attitudes towards Children with Epilepsy among Egyptian Parents: A Comparative Cross-Sectional

Study. *Epilepsy Research*, 172, 106573. doi: 10.1016/j.eplesyres.2021.106573

Ferro MA, Avery L, Fayed N, Streiner DL, Cunningham CE, Boyle MH, et al. (2017). Child and Parent-reported quality of life trajectories in children with epilepsy: a prospective cohort study. *Epilepsia*; 58:1277–86.

Ferro MA, Goodwin SW, Sabaz M, Speechley KN. (2016). Measurement Equivalence of the newly developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). *Epilepsia*; 57(3):427-35.

Gotil A, Dihora R, Desai S. (2020). Assessment of quality of life in parents of epileptic children and its associated factors. *International Journal of Contemporary Pediatrics*; 8(9):1-7 <http://www.ijpediatrics.com> DOI: Error! Hyperlink reference not valid.

Hagemann A, Pfafflin M, Nussbeck FW et al. (2016). The efficacy of an educational program for parents of children with epilepsy (FAMOSEs): Results of a controlled multicenter evaluation study. *Epilepsy and behavior*, 64:143-151.

Hassan AA, Yahya MA, Tariq AA, Hussamaldin Tariq AA. (2018). Assessment of knowledge and Attitude and Practice of Parents towards Epilepsy among Children in Abha City. *The Egyptian*

Journal of Hospital Medicine, 72(3), 4060-4063. doi: 10.21608/ejhm.2018.91164.

Horaib W, Alshamsi R, Zabeeri N, et al. (2021). Quality of Life and the Perceived Impact of Epilepsy in Children and Adolescents in the Eastern Province of the Kingdom of Saudi Arabia. *Cureus* 13(12): e20305. DOI 10.7759/cureus.20305

Jonsson P, Jonsson B, and Eeg- Olofsson O (2014). Psychological and Social Outcome of Epilepsy in Well- functioning Children and Adolescents. A 10 Year Follow -up Study. *European Journal of Pediatric Neurology*; 3: 1-10.

Karnavat PK, Hegde AU & Kulkarni S. (2018). Quality of Life in Children with Epilepsy in Private and Public Tertiary Care Centers in India. *International Journal of Epilepsy*, 5 (01): 028-37.

Katibeh P , Inaloo S , Jafari P, Fattah F, Mazloomi S. (2020). Evaluation of the Quality of Life in Epileptic Children of Shiraz, Southern Iran. *Iran J Child Neurol*. Spring; 14(2): 59-68

Khedr EM, El-Fetoh NA, Thabit MN, Abass MA, & Fawzi G (2013). A community based epidemiological study of epilepsy in Assiut Governorate/Egypt. *Epilepsy research*; 103(2):294-302.

Nadkarni J, Jain A & Dwivedi R. (2011). Quality of life in children with epilepsy. *Ann Indian Acad Neurol*; 14(4):279–282.

Nagabushana D, Praveen-Kumar S & Agadi J. (2019). Impact of epilepsy and antiepileptic drugs on health and quality of life in Indian children. *Epilepsy Behav.* Apr; 93:43-48. doi: 10.1016/j.yebeh.2019.01.021.

Neyaz HA, Aboauf HA, Alhejaili ME et al. (2017). Knowledge and attitudes towards epilepsy in Saudi families. *Journal of Taibah University Medical Sciences*, 12:89-95.

Nishina Y & Yoshioka S. (2018). A Survey of Epilepsy-related Knowledge, Attitudes and Practices of Home Healthcare Nurses in the San-in Region of Japan. *Yonago Acta Medica*, 61(1), 019-026. doi: 10.33160/yam.2018.03.003. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5871722/>

Olusanya BO, Wright SM, Nair MK et al. (2020). Global Research on Developmental Disabilities Collaborators (GRDDC). Global burden of childhood epilepsy, intellectual disability, and sensory impairments. *Pediatrics*, 146(1):e20192623

Osman MI, Bazie EA, Alamin AM et al. (2021). Knowledge, Attitude, and Practice of Caregivers among Epileptic Pediatric Patients in Jafer Ibn Auf Hospital-Khartoum-Sudan. *J Pediatr Neonatal*; 3(2): 1-4.

Pachange PN, Dixit JV, Arjun M C & Goel AD. (2021). Quality of Life among Middle and Secondary School Children with Epilepsy. *Journal of Neurosciences in Rural Practice*. 12. (3):490-494

Riechmanna J et al. (2019). Quality of life and correlating factors in children, adolescents with epilepsy, and their caregivers: A cross-sectional multicenter study from Germany. *Seizure: European Journal of Epilepsy*, 69: 92–98

Shahin MAH & Hussien RM. (2021). Knowledge, attitude, practice and self-efficacy of caregivers of children with epilepsy: impact of structured educational intervention program. *Journal of Japan Epilepsy Society*. 13 (1):1-16

Shihata SS, Abdullah TS, Alfaiidi AM, Alasmari AA, Alfaiidi TM, Bifari AE, Wisam H Jamal WH & Rizk HA. (2021): Knowledge, perception and attitudes toward epilepsy among medical students at King Abdulaziz University. *SAGE Open Medicine*. 9: 1– 6

World Health Organization (WHO). (2019). Epilepsy, Key facts. Available at: <https://www.who.int/news-room/factsheets/detail/epilepsy> (last accessed; 27/6/2019)